

10 facts everyone should know about Transverse Myelitis

1. Transverse Myelitis (TM) is a rare disease of the central nervous system involving inflammation in the spinal cord.

Around 300 new cases are diagnosed each year in the UK. Related conditions include ADEM (Acute Disseminated Encephalomyelitis), NMO (Neuromyelitis Optica, or Devic's Disease), ON (Optic Neuritis) and MS (Multiple Sclerosis).

2. TM is not hereditary or contagious.

You cannot pass on an increased risk of getting TM to your family.

3. Transverse Myelitis can affect anyone, at anytime, anywhere.

TM affects people of all ages from 5 months to 80 years. However the peak ages for a TM diagnosis appear to be 10-19 and 30-39 years. Men are equally likely to be diagnosed as women.

4. Everyone with TM is affected differently.

The main symptoms of TM are muscle weakness in the legs (and, less commonly, in the arms), change in sensation (unusual feelings) in the lower half of the body, pain, and problems with the bowel and bladder. People might also experience fever, headache, tiredness, muscle spasms (spasticity), and a general feeling of being unwell. But symptoms vary depending on what section of the spinal cord is affected.

5. Recovery is difficult to predict.

Around one third of people with TM will make a good or full recovery. Another third will experience some recovery and may have a moderate degree of disability. The remainder will make little or no recovery and have a permanent disability. Recovery usually begins within two months and can continue for up to two years and beyond.

6. Nobody knows what causes TM.

It is not always possible to identify the cause of TM. When inflammation happens it is thought to be the result of the immune system mistakenly attacking the spinal cord. TM often develops at the same time as, or soon after, a viral or bacterial infection and, rarely, after vaccinations.

7. TM is a ‘hidden disability’.

Whilst some people with TM may use a wheelchair for all or part of the time, others may have no visible symptoms. Just because the person looks healthy, it does not mean they are feeling fine. A person with TM may not dwell on their condition, or may minimise the effect it has on them as a coping strategy.

8. Average GP sees a case of TM once every 100 years.

The condition is so rare many GPs have not heard of TM. This can complicate diagnosis.

9. Diagnosing TM is not straightforward.

The onset of TM is often sudden, and can be at its most severe state in just hours. For others, symptoms develop slowly over several weeks. Common first symptoms can include pain in the back, torso or extremities, mobility issues, and a burning or tingling feeling in the legs. Key tests to diagnose TM is MRI scan of the spine and brain, lumbar puncture, eye evoke potentials and blood work.

10. There is currently no cure for TM.

The most common form of treatment is corticosteroids, intravenous immunoglobulin, and sometimes plasma exchange. Pain relief medication for neuropathic pain is prescribed where needed. Issues with balance, mobility, spasticity, and pain can also be treated through neuro-physiotherapy.

Support the TM Society and help reduce the isolation many people living with Transverse Myelitis and related conditions feel.

Facts used are taken from the TM Society (www.myelitis.org.uk) and the Brain & Spine Foundation (www.brainandspine.org.uk).